Concurrent Session One – Translation Issues/Taxonomy Populations

Kira Sloop Facilitator
ORC Macro

Ms. Sloop called the session to order. She explained the purpose and the format of the session, and then introduced the panel members who delivered overview presentations, and/or engaged in deliberations with the participants.

Kelly Bartholow
CDC/PERB
CDC Representative

Kelly Bartholow presented the categories of populations that interventions are designed to address:

- ❏ Men who have Sex with Men (MSM) covers both men who report sexual contact with men and men who report sexual contact with both men and women.
- ❏ MSM-IDU is the MSM population that also reports injection drug use.
- ❏ Injection Drug Use (IDU) are people who are at risk for HIV infection through the use of equipment used to inject drugs.
- ❏ Heterosexual covers people who have had heterosexual contact with people at increased risk for HIV infection.
- ❏ Mothers With or At Risk for HIV targets women who are pregnant and either at risk of being HIV-infected or who are HIV-infected and risk transferring HIV to the infant.
- ❏ General population interventions are not particularly directed toward people at risk, but to the population as a whole.

Tippavan Nagachinta
CDC/CBB
CDC Representative

Tippavan Nagachinta, of the Science Application Team, spoke to the group about available technical assistance (TA) for them. She indicated that technical assistance comes from three sources:

- ❑ NASTAD, which offers peer-to-peer technical assistance for health departments;
- ❑ MACRO, which provides TA to states in the area of evaluation; and
- ❑ CDC, which offers TA to states via the Science Application Team and the Program Evaluation and Research Branch.

To access technical assistance, she said it is recommended that health departments contact their Project Officer, who sends requests to the appropriate TA provider according to the request. The types of available technical assistance are:

- ❑ Interpretation of the Health Department Evaluation Guidance;
- ❑ Clarification of terms and CDC expectations;
- ❑ How to ascertain the scientific basis of prevention programs;
- ❑ Process monitoring and process evaluation;
- ❑ Outcome monitoring and evaluation;
- ❑ Data collection and management procedures; and
- ❑ Strategies to improve quality assurance.

There are some limitations to technical assistance, which include:

- ❑ Data management software;
- ❑ CDC cannot do evaluations or analyze data for health departments;
- ❑ CDC cannot come to states and conduct basic training on the Evaluation Guidance to CBOs and contractors; however, CDC can offer nationally-distributed trainings on evaluation to increase health department evaluation capacity;
- ❑ CDC can only provide TA and cannot do the work.

She reinforced that health departments should seek assistance via their Project Officers.

Reverend Tommie Watkins
CBO Peer
Greater Bethel AME Church

Reverend Tommie Watkins, from the Greater Bethel AME Church in Miami, Florida, is the Program Director of an HIV Prevention Education Program that works with the health department. He explained that their faith-based initiative began about six years ago. In communities of people of color, the church is the most powerful entity; therefore, they moved toward a program that is progressive and that addresses the needs of their community. They accomplish this goal through the HIV Partnership Prevention Plan. In Miami/Dade County, the main target population is Black MSMs and their partners, and the second target group is Black women, which includes Creole, Haitian, and African-American groups.

They reach their populations through prevention education, going to schools and other churches, where they make condoms available. They also conduct a two-hour weekly group-level intervention that helps their populations empower themselves. The curriculum lasts for twelve weeks, and its goal is to encourage men to talk about all issues that they encounter, including their sexuality. A women's group meets twice a month called "Self Help and Empowerment Group," or "The SHE Hour." In addition, they have a street and community outreach intervention, wherein they conduct risk and needs assessments in the field and invite members of the target population into their Prevention Case Management component. They link their clients with other case management agencies, but they mainly focus on prevention case management.

Reverend Watkins encouraged the group to consider faith-based initiatives and to look at progressive churches as sources for help. His program has found that in the faith community, there are many pastors who want to address HIV, but they do not want to talk about sex and sexuality. Two Sundays a month, they have a program called "The Ministry of Reconciliation," where the church opens its doors to people who have HIV and who identify as having different sexual orientations. It is a non-threatening, inclusive, and affirming environment from an African-American perspective in a traditional denomination. It helps people heal who have been marginalized from the Black church. They use the book *Black Church and Sexuality* by Dr. Kelly Brown Douglas, which includes a twelve-week curriculum, and then follow the book study with a traditional worship service. They also use *The Good Book*, by Reverend Peter J. Gomes, an African-American Baptist who identifies himself as a homosexual. His book takes the Bible from an historical, critical perspective, because traditionally, barriers to faith-based initiatives have included the interpretation of Scripture.

In conclusion, Reverend Watkins said that they collaborate with the health department and other CBOs to try to meet the needs of the people.

Discussion Summary:

- An audience member asked Reverend Watkins to what extent they were able to engage MSMs who do not identify themselves as gay; and if so, how they are able to do so.

- Reverend Watkins responded that Miami is unique in that its population is segmented due to its cultural and ethnic differences. The Black gay community is nearly invisible in the county. Many people commute to Ft. Lauderdale and to other cities that have a more inclusive environment. Their approach is to go to straight bars and to distribute their empowerment and support group information. When people see a church that is open and affirming about sex and sexuality, they often open a dialogue about being tested and other issues. The church also has a media campaign, which has resulted in people contacting the church for services. They have also addressed the barrier of traditional, Biblical rhetoric to MSMs by moving to publish a pamphlet that addresses those

Scriptures that many people say are damning to MSMs or WSWs. This pamphlet will give perspective on what the Bible really *says* and what the Bible really *means*. Their initiative is to include this pamphlet in a packet with a condom and their empowerment information. People may not adopt their theology. He stressed that they are not out to convert people. All they want is to educate people, which is why their interventions are aimed at prevention education.

Marquietta Alston
Health Department Peer
Virginia Health Department

Marquietta Alston spoke about how their department included the CDC-identified risk behavior populations with the state's taxonomy. Before the Guidance, Virginia collected mostly process and monitoring data. This data included gender, types of sessions, and evaluation. The contractors were required to apply some of their budget to evaluation, reinforcing the importance of evaluation. With this preparation, the Guidance was not foreign to them. The Guidance still raised many questions concerning the populations about which they would be collecting information. A formula was already in place for prioritizing populations, which included factors such as:

- ❏ Risk
- ❏ Need
- ❏ HIV/AIDS statistics for specific populations, which were then compared to the general population
- ❏ Funding directed to certain populations
- ❏ Information gathered from town meetings
- ❏ Other factors

At the outset, the contractors wanted to keep their initial populations. After the initial resistance, though, they were able to work together to make the two languages mesh.

After looking at CDC's definitions and comparing them to Virginia's definitions, they found commonalities and used CDC's definitions to define their priority populations. Finally, they were able to combine the languages. The categories included:

- ❏ Racial/ethnic minorities
- ❏ MSMs
- ❏ Women
- ❏ Youth
- ❏ PWAs
- ❏ Homeless

- ❑ Sex workers
- ❑ Mentally dysfunctional inmates
- ❑ General population

Marquietta Alston pointed out that homeless, sex workers, and mentally dysfunctional inmates represent "special populations" It is difficult to gather statistics on these populations, but there are reasons that they are at-risk, so Virginia still wanted to include them in their taxonomy.

Contractors identify their intervention's target population, the intervention that they are using, and then they check each of the categories that applies to their population. They also have to specify the risk behavior that they are trying to address. The health department requires quarterly reports on which contractors can indicate the total number of people served, their progress toward their goals, and the numbers of people that they have reached in each category. This method incorporates quality control into the contractors' system and allows them to make changes in their programs if they find that they are not reaching whom they wanted or expected to reach.

She stressed that combining the language does not eliminate all problems. For instance, the homeless population's risk levels and characteristics are difficult to predict, so the health department asks its contractors to do their best when making their projections. Many of them use past experience for those estimations. The same problems surface with the incarcerated population. Sometimes contractors can guess what risk behaviors they will find, and then can address those interventions.

Marquietta Alston said she doubts that in the future they will ever use just the CDC terms. Her understanding of the Guidance is that it was not meant to replace or minimize efforts that are already in place. CDC merely needs a common language to make national reports of what is being addressed in HIV programs. In the prioritization process, the categories may change slightly; for instance, the group "women" may be combined with the "heterosexual" category. There is no one answer to the problem, she concluded, but the combination of languages has made collection easier for their contractors, and they are still able to aggregate the data for CDC while satisfying needs at the local level.

Discussion Summary:

- ❖ A member of the audience asked Marquietta Alston to describe the difference between basic street outreach, intensive street outreach, facilitated street outreach, and collaborative street outreach.

- ❖ Marquietta Alston replied that *Basic street outreach* was a means to go into the community to distribute information with little engagement – it is not an intervention, but

a strategy. *Intensive street outreach* incorporates more contacts and more lengthy encounters and may have an informal risk assessment component. It may also include a referral. *Facilitated street outreach*, which follows the other two, involves making an appointment for one-on-one with a person. *Collaborative street outreach* includes more stringent follow-up, which may push the envelope of case management. Essentially, the different types of outreach represent different levels of contact. She added that collaborative and facilitated outreach may include a transportation component.

- Another audience member observed that the progression seems to be from outreach into individual-level intervention. Collaborative outreach also includes work with other agencies.

- Mary Parsons, also from the Virginia Department of Health, further clarified the procedure for making appointments with people encountered during these interventions, pointing out that there are multiple contacts with clients, which lead to the more formalized "appointments."

- Another participant remarked that the idea of specificity in target populations at the local level is a good idea. The focus is trying to translate those categories into transmission risk.

- With that in mind, an inquiry was posed as to whether her group had developed a profile sheet for contractors to complete at every encounter.

- Marquietta. Alston replied that the health department had not stipulated the use of a certain collection tool. They have provided samples of tools to contractors and samples of risk assessment tools, but have left the collection methods up to them.

- A question was posed as to whether, when they collect data from contractors, it is in aggregate form or at the individual level.

- Marquietta Alston replied that the contractors collect their data by population and by intervention. The health department then aggregates the data.

- Another audience member asked about working with trans-genders.

- Marquietta Alston said that they have addressed the topic, and have encouraged their contractors to focus on a particular risk behavior rather than trying to classify the person at risk. Work in that population is minimal in her state.

- An inquiry was posed by a participant, whose CPG has prioritized four categories of

youth, as to how Virginia classifies youth.

- ❖ Marquietta Alston replied that in some interventions, there might not be direct questioning of risk behaviors. The question regards what behaviors are being addresses. In Virginia, the focus is on heterosexual and young MSM groups. Rarely do contractors put down IDU. She said that while much of the work is estimated, they try to get self-reported risk assessments.

Kira Sloop then had the participants in this session break into smaller groups. She pointed out that there are great examples from a variety of sources. Virginia's strategy of combining languages is but one option. Other local departments are opting to use only their own terms, and then the state health department translates the data at that level to send to CDC. A third strategy is adopting the CDC taxonomy uniformly and requiring contractors to do the same. Any of these strategies might apply to a given jurisdiction. She requested that they discuss their options in their small groups, and then assign someone to report out to the larger group. The report from these breakout sessions included the following feedback:

Table #1:

- ❑ Washington state totally uses CDC's risk behavior population, having decided after much discussion that it would be easiest to collect information the way it would have to be reported to CDC.
- ❑ Vermont is also using CDC's risk behavior population taxonomy.
- ❑ Virginia uses a combination of methods, as discussed in the presentation.

Table #2:

- ❑ Pennsylvania has thirteen different population categories, and Iowa has seventeen different population categories. Some programs are doing the translation for the grantees, while others are asking the CPG to use the CDC category to prioritize their populations, moving toward using CDC categories.
- ❑ One strategy for collecting data is used in Maryland, where all interventions except for outreach use some kind of risk assessment tool that is self-administered and turned into the health department.
- ❑ In Alaska, the approach is to go by the intended population of the intervention.

Table #3:

- ❑ New York City uses the third strategy, which is having contractors use both CDC and their own local terms, which is similar to Virginia's approach, but more detailed.

- ❏ Utah's contractors use the CDC taxonomy exclusively, and they have a system whereby contractors and sub-contractors can use a website to send their aggregated data directly to the health department.
- ❏ Major challenges include getting the local level to come to a uniform language. It was the consensus that the health department is the translator of the information to CDC.

Table #4:

- ❏ All states at this table (Florida, Georgia, New York State, and the Federated States of Micronesia) use a combination of local and CDC taxonomies. Once the CBOs report in local terms, the health department translates that information for CDC purposes.
- ❏ Challenges arise in risk behaviors and in comparing them to populations.
- ❏ Target populations such as youth and women that are not addressed by the CDC terminology are captured in the local taxonomies.

Discussion Summary:

- ❖ A representative from Alaska noted that according to the CDC Guidance, HIV-positive persons are not being captured, despite national attention being directed toward interventions in that population. In her state, they completed an RFP process to fund grantees to do interventions for HIV-positive persons. They can collect data according to the risk factors of that population, which satisfies grant oversight at the local level, but in reporting those interventions to CDC, they will be classified by risk populations. The current Evaluation Guidance Data System will not be able to provide CDC at the national level with information about what interventions and what resources are aimed at HIV-positive persons.

- ❖ A CDC representative said they appreciated the comment, adding that distinguishing between transmission categories and other data sets is an issue to be addressed. It could represent an additional data element without changing the data set entirely.

- ❖ Another participant raised the issue of how to place non-identified MSMs in the plan. Is it general population work, community-level intervention, or is it reaching MSMs? Her thought was to follow the intent of the intervention. Her group also discussed the risk categories for substance use and how to address the risk that comes from use of other substances and other contributing factors. They concluded that there is no way to capture when the substance use brings the highest risk.

- ❖ Reverend Watkins noted that his table had touched on the same issue, which includes topics of cultural sensitivity. With their next round of RFPs, he said they have chosen to address men, women, and youth "to include men who have sex with men and women

who have sex with women." They are trying to remove stigma from the group and to be more inclusive. Their work with the prison population has yielded more open identification of risk. He stressed that they must remember that the risk is men having sex with men, but the population is Black men.

- A participant from New York City remarked that the new reporting tables do not include a method to determine the number of non-Hispanic Whites. It is not clear how the CDC manages that. There are black Hispanics, et cetera, and a cross-tab is not possible in that category. Traditionally, he said that when Hispanic is a co-equal category with other races, it is possible to break out non-Hispanic White, non-Hispanic Blacks, et cetera. Estimates are possible, but not concrete numbers. Another group member described a recent study in which they found that many Latinos did not check any race on their forms. After consulting with CBO's, they discovered that Latinos do not know how to identify with a "race" as they have never been defined in such a way. A similar confusion, which may come from not educating the community, occurs with Native Americans.

- A participant from Washington, D.C. commented that the age groups are too broad at both the young and the elderly ends of the spectrum.

- Kata Chillag responded that CDC realizes that there are limitations to the categories, which are often created by the Office of Management and Budget. They want to know the nuances of local situations, but they also want a very basic way to communicate, using similar categories. They hope that future activities will give them opportunities for cross-tabs. They encourage local, user-defined categories which can be included in the narrative sections of the reports.

- Nikki Economou asked the audience to share their challenges and experiences, including how CDC can help them go from where they are to where they need to be. A group member commented that conferences and session such as this one are very beneficial and that they would appreciate more workgroups with specific agendas that could generate recommendations for future changes and work. Then, work at the local level can have an impact on the national Guidance and its revisions.

- A participant noted that consistent communication is the best way that CDC can help the health departments. Even a website with questions and answers that are accessible to everyone can help with TA. This site could also act as a clearing house for questions and comments and a listserv. CDC may not have all the answers. Other jurisdictions may have answers from their experiences and successes. Nikki Economou agreed that good answers come from the field.

- ❖ It was noted by a participant that materials or TA for the Latino population that could then be translated to the CBOs to collect data, would help alleviate the problems that they have with collecting information in their population. He also asked about the development of software for CBOs to be able to collect their own data.

- ❖ A CDC representative answered that software for directly-funded CBOs was being developed, which would complement the upcoming health department software.

- ❖ An attendee from Georgia commented that CDC had worked with them to modify ERAS to be included at the local level, and they would pilot that project in January.

- ❖ Nikki Economou added that health departments want and need information from directly-funded CBOs so that they can fill in any gaps, and so they can share information.

- ❖ Gary Uhl described a study that would involve going to six health departments and asking them what they need to conduct program evaluation better. He said that they would try to reach states that had a greater need.

- ❖ Nikki Economou said that they plan to share that information with the Division at CDC to help with capacity-building and other resources. Low-incidence states do not get enough attention.

In conclusion, audience members agreed that health departments need the following from CDC:

- ❑ Financial resources to set up evaluation systems
- ❑ Clear guidance
- ❑ Consistency so that they can catch up